Artificial Enteral Nutrition in Advanced & Terminal Illness:
What does the literature really say?

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Case Presentation

90 yo AA female is sent to the emergency room from her nursing home.

Brief History:

She was discharged from the neurology service one week prior after a massive MCA stroke which left her minimally responsive
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Brief History:
She was discharged from the neurology service one week prior after a massive MCA stroke which left her minimally responsive
Case Presentation

- Given the poor prognosis, the patient was referred to Hospice by the neurology service. Her family agreed upon end of life care. She was sent to a nursing home without IV fluids or tube feeds. The family expected her to pass within several days.
Hospital Course

☐ Her family was concerned that she had not received any food or water for the past week. They feared she was suffering from starvation. In addition, they rescinded her DNR/DNI code status.

☐ The patient was admitted that night for PEG tube placement.
Clinical Judgment

- As there had been no improvement in her neurological status, we felt strongly that the patient would not benefit from the insertion of a PEG tube.
- Despite the team’s concern, the family demanded that the patient be fed.
Outcome

- Upon the family’s insistence, the patient was fed and rehydrated. A PEG tube was inserted and tube feeds begun. She expired 2 days later, in the Palliative Care Unit, from an aspiration pneumonia.
Outcomes

- No study has demonstrated decreased pneumonia through tube feeds
- No randomized studies
- Swallowing studies lack both specificity and sensitivity in predicting who will aspirate

(Croghan, 1994)
Outcomes

- Where tube feedings likeliest to prolong life
  - Reversible catabolic illness (sepsis, burn, post-surgery)
  - H & N tumors with proximal OP involvement
  - Chemo or XRT involving proximal gut
Recent prospective data
(Meier, et al., Arch Int Med, 2001)
192 patients eligible
99 enrolled (10 PCP’s refused, no surrogate found for 89)
Randomly assigned to intervention or control
Outcomes

- Median age: 84.0 yrs
- Females: 81%
- Length of stay: 12 d (2-93)
- Number with tubes placed: 51%
Outcomes

- Intervention (counseling on palliative care) had no effect on any outcomes
- Factors associated with tube placement:
  - African American (hazard ratio 9.4)
  - Nursing home resident (4.9)
Outcomes

- More than half of all patients could not be enrolled because of a lack of surrogate
- 50% 6-month mortality irrespective of tube placement
Agenda

- Who gets a PEG tube?
- Do PEG tubes change survival/mortality?
- Do PEG tubes:
  - decrease aspiration pneumonia?
  - improve nutritional status?
  - help prevent or heal pressure ulcers?
- Why do we do what we do?
- Where do we go from here?
PEG Tubes

- Neurological disorders
  - Dementia
  - CVA
  - ALS
  - PD, MS, MG

- Head and neck cancer
- Esophageal obstruction
- Gastric outlet obstruction
- Critical illness
- Terminal illness

Cognitive Impairment

- Defined by limitations in self care performance
- Signs:
  - Memory loss
  - Impaired communication
  - Inappropriate affect
  - Personal care difficulties
  - Hazardous behavior
- MMSE
- Cognitive Performance Scale
CPS

- Coma: 0-1
- Short term memory: 0-1
- Cognitive skills for Decision Making: 0-3
- Making self-understood: 0-3
- Eating ADL: self performance: 0-4

<table>
<thead>
<tr>
<th>CPS</th>
<th>MMS (Mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intact = 0</td>
<td>24.9</td>
</tr>
<tr>
<td>Borderline intact = 1</td>
<td>21.9</td>
</tr>
<tr>
<td>Mild impairment = 2</td>
<td>19.2</td>
</tr>
<tr>
<td>Moderate impairment = 3</td>
<td>15.4</td>
</tr>
<tr>
<td>Mod-severe impairment = 4</td>
<td>6.9</td>
</tr>
<tr>
<td>Severe impairment = 5</td>
<td>5.1</td>
</tr>
<tr>
<td>Very severe impairment = 6</td>
<td>0.4</td>
</tr>
</tbody>
</table>
SNF + CI = PEG

www.chcr.brown.edu
## North Carolina 2000

<table>
<thead>
<tr>
<th>Procedure</th>
<th>NC</th>
<th>US</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use of feeding tubes in cognitive impairment</td>
<td>27.1%</td>
<td>21.5%</td>
</tr>
<tr>
<td>Orders to forego in cognitively impaired</td>
<td>4.8%</td>
<td>11.0%</td>
</tr>
<tr>
<td>Orders to forego in terminally ill SNF residents</td>
<td>4.5%</td>
<td>14.5%</td>
</tr>
<tr>
<td>Orders to forego in all SNF residents</td>
<td>3.2%</td>
<td>9.0%</td>
</tr>
</tbody>
</table>

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Who gets a PEG?

- Washington State - 24 months
  - N = 1386 SNF residents
    - 65 years or older
    - Progression to CPS 6
    - No PEG at outset

- PEG → 9.7%

Associated factors

- < 87 years old
- Aspiration
- Dysphagia
- Pressure ulcer
- Stroke
- No DNR
- No dementia

SNFs & Their Residents

- 1999 MDS
  - CPS 6 – 186,835
  - CPS 6 + PEG = 63,101 (34%)

- OSCAR
  - N = 15,135

Clinical Characteristics

- Younger age
- Divorced
- Non-white race
- Male
- No advance directives
- Recent decline
- Not Alzheimer’s

Organizational Characteristics

- For-profit status
- > 100 beds
- No NP or PA on staff
- Fewer “DNRs”
- Urban location
- No dementia unit

Who gets a PEG tube?

- 6/94-12/97 SNF residents
  - NY state
  - CPS 5-6 or terminal cancer
  - Dead by 1 year
  - ≥ 65 years

N = 2492
- 1609 advanced dementia
  - PEG – 25%
- 883 terminal cancer
  - PEG – 5.2%

ACP & AOR (Dementia v. Cancer)
- DNR 0.12
- DNH 0.33
- No TF 0.56

· Signs/Sxs & AOR (Dementia v. Cancer)
  - Pressure ulcer 1.69
  - Pneumonia 2.28
  - Fever 1.52
Survival

- VA Study 1990-1992
- N = 7369 with PEG
  - Mean Age = 68 years
  - CVA 18.9%
  - Other CNS disease 28.6%
    - Alzheimer’s
    - ALS
    - MS
  - Head and neck CA 15.7%
  - Nutritional deficiency 10.9%

- Median survival 7.5 months

- Inpatient mortality
  - <65 – 18.9%
  - 65-74 – 24.7%
  - >75 – 27.5%

- Mortality Rates
  - 1 year – 59%
  - 2 years – 71%
  - 3 years 77%

Survival - Cognitive Impairment

- 1386 NH residents
  - 65 years or older
  - 9.7% PEG vs. control without PEG
- Associated factors
  - < 87 years old
  - Aspiration
  - Dysphagia
  - Pressure ulcer
  - Stroke
  - No DNR
  - No dementia

Poorer Survival

- Aspiration
- Chewing & swallowing problems
- > 87 years
- Pressure ulcers
- Stroke
- No dementia
- DNR

Mortality S/P Hospitalization

- 1991
- $N = 81,105$
- $\geq 65$ years + Gastrostomy tube
  - PEG = 59,969
  - Surgical G tube = 21,136

Table 2.—Frequent Discharge Diagnoses for Hospitalized Medicare Beneficiaries Discharged in 1991 Following Gastrostomy Placement

<table>
<thead>
<tr>
<th>Primary diagnoses</th>
<th>Women, No. (%)</th>
<th>Men, No. (%)</th>
<th>Total, No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerebrovascular disease</td>
<td>8898 (18.1)</td>
<td>5512 (17.2)</td>
<td>14410 (17.8)</td>
</tr>
<tr>
<td>Neoplasms</td>
<td>3631 (7.4)</td>
<td>3975 (12.4)</td>
<td>7606 (9.4)</td>
</tr>
<tr>
<td>Fluid and electrolyte disorders</td>
<td>4935 (10.1)</td>
<td>2505 (7.8)</td>
<td>7440 (9.2)</td>
</tr>
<tr>
<td>Aspiration pneumonia</td>
<td>3346 (6.8)</td>
<td>3361 (10.5)</td>
<td>6707 (8.3)</td>
</tr>
<tr>
<td>Pneumonia or influenza</td>
<td>2926 (6.0)</td>
<td>2415 (7.5)</td>
<td>5341 (6.6)</td>
</tr>
<tr>
<td>Malnutrition</td>
<td>2492 (5.1)</td>
<td>1083 (3.4)</td>
<td>3575 (4.4)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Secondary diagnoses*</th>
<th>Women, No. (%)</th>
<th>Men, No. (%)</th>
<th>Total, No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fluid and electrolyte disorders</td>
<td>19083 (38.9)</td>
<td>10775 (33.6)</td>
<td>29858 (36.8)</td>
</tr>
<tr>
<td>Urinary tract infection</td>
<td>15079 (30.7)</td>
<td>6208 (19.4)</td>
<td>21287 (26.2)</td>
</tr>
<tr>
<td>Malnutrition</td>
<td>11647 (23.7)</td>
<td>6942 (21.7)</td>
<td>18589 (22.9)</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>7097 (14.5)</td>
<td>3835 (12.0)</td>
<td>10932 (13.5)</td>
</tr>
<tr>
<td>Neoplasms</td>
<td>4830 (9.8)</td>
<td>5295 (16.5)</td>
<td>10125 (12.5)</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>5923 (12.1)</td>
<td>3915 (12.2)</td>
<td>9838 (12.1)</td>
</tr>
<tr>
<td>Dementia</td>
<td>6007 (12.2)</td>
<td>2661 (8.3)</td>
<td>8668 (10.7)</td>
</tr>
<tr>
<td>Swallowing disorders</td>
<td>5112 (10.4)</td>
<td>3387 (10.6)</td>
<td>8499 (10.5)</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>5426 (11.1)</td>
<td>3004 (9.4)</td>
<td>8430 (10.4)</td>
</tr>
<tr>
<td>Obstructive pulmonary disease</td>
<td>3431 (7.0)</td>
<td>4933 (15.4)</td>
<td>8364 (10.3)</td>
</tr>
<tr>
<td>Decubitus ulcer</td>
<td>4963 (10.1)</td>
<td>2578 (8.0)</td>
<td>7541 (9.3)</td>
</tr>
</tbody>
</table>

☐ Median survival
- Males 17.6 weeks
- Females 28.9 weeks

☐ Mortality rates
- 30 day = 23.9%
- 1 year = 63%
- 3 years = 81%

Mortality with PEG

- United Kingdom
- 8/92-7/97
- N = 361
- Sample
  - Grp 1 – oropharyngeal malignancy
  - Grp 2 – acute CVA with dysphagia
  - Grp 3 – dementia
  - Grp 4 – miscellaneous (head injury, MND, MS, CP, HIV, PD)

Mortality in all groups
- 30 days – 28%
- 1 year – 63%

Group 3 Mortality
- 30 days – 54%
- 1 year – 90%
Survival SNF Residents

- Incident MDS level 4 eating dependence + swallowing disorder

- N = 1545
  - PEG 353
  - No PEG 1192

1 year survival
- PEG 50%
- No PEG 39%
- Risk ratio = 0.71 (0.59-0.86)

CPS $\geq 5 = 63\%$
Mortality

- 99 hospitalized patients
  - Dementia FAST ≥ 6D
  - 50% with PEG placed

- Associated factors & Hazard ratio
  - SNF residence – 4.9
  - Advance directive - 0.32
  - African American - 9.4

- Median LOS – 12 days
- Median survival – 175 days
- PEG = No PEG
Aspiration Pneumonia

- N = 104
- 87 years old
  - 52 with PEG
    - MMSE = 0
  - 52 without
    - MMSE < 23 in 71%

- Most common indication
  - wt loss despite dietary supplement
  - need for assisted feeding

Apiration by 6 months

- PEG – 57%
- No PEG – 17%

Aspiration Pneumonia

- VA Study
- N = 109

- PEG – 80
  - 85% ≥ 1 neuro dx
  - Dysphagia 79%
  - Refusal to eat 14%

- NET – 29
  - 79% ≥ 1 neuro disorder
  - Dysphagia 41%
  - Refusal to eat 41%

- Aspiration pneumonia
  - 14 days
  - PEG 6%
  - NET 24%
  - No difference in cumulative episodes

- No advantages in survival, nutrition, or performance status

PEG vs. PEJ

- N = 79
  - Neurologic disorders
  - Cancer

- Aspiration 9 (11.4%)
  - 6 with PEJ to prevent aspiration
  - 100% aspirated
  - 3 died of continued aspiration

J Tubes

- N = 44
  - Neurologic 61%
  - Non-neurologic 39%

- Aspiration
  - 19 pre-J tube
    - 31% continued
  - 1 de novo

Nutritional Benefits

- N = 40
  - Chronically ill
  - Poor functional and cognitive status
  - PEG tube

- 3 months controlled anthropometric, biochemical, clinical and dietary data

- Continued weight loss

- Micronutrient deficiencies and marasmic malnutrition
Nutrition Outcomes

- Community study
- N = 150
  - Mean age 78.9 years
  - CVA 40.7%
  - Neurodegenerative 34.7%
  - Cancer 13.3%

Callahan CM et al. JAGS 2000; 48:1048-1054.
- BMI
- Triceps skin fold thickness
- Albumin
- Cholesterol

- Mortality
  - 7 day 10%
  - 30 day 22%
  - 1 year 50%

Callahan CM et al. JAGS 2000; 48:1048-1054.
### 4 Month Follow-up

<table>
<thead>
<tr>
<th>Parameter</th>
<th>% improved</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMI</td>
<td>0</td>
</tr>
<tr>
<td>TSFT</td>
<td>8.9</td>
</tr>
<tr>
<td>Albumin</td>
<td>29.8</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>16.7</td>
</tr>
</tbody>
</table>

Callahan CM et al. JAGS 2000; 48:1048-1054.
Tube Feeding and Pressure Ulcers

- PEG use in SNF
- N = 104
- Advanced dementia
- PEG vs No PEG
  - PU 21% vs 14% control

Related to incontinence, restraints

Restraints
- 71% with PEG
- 56% without PEG
Pressure ulcers

- 129 hospitalized with hip fracture
  - 62 with tube feeds via NG
  - 67 without

- 1 and 2 week monitoring
  - Protein intake
  - Hemoglobin
  - Serum albumin
  - Serum protein

With tube feeds
- 25 tolerated tube x 1 week
- 16 x 2 weeks
- 2-3x higher protein intake
- No change in serum protein and albumin

No difference ulcers

Commons Burdens with Tube Feeding

- Restraints
- Aspiration pneumonia
- Increased risk of infection
- Nausea/Vomiting/Diarrhea
- Decreased human interaction
- Development of bed sores

Family Beliefs Regarding Nutrition

- Grounded theory method
  - Patients
  - Family
  - Bereaved family
  - HCP

- PCU
  - Terminal cancer
  - U of Manntoba

“Doing what’s best…”

- “Fighting back”
  - “Well, if you don’t have gas in the car…”

- “Letting nature take its course”
  - “You eat what you can…”

- “Waffling”
  - “Yes, I knew that he was terminal, but…”
Physician Beliefs

- 500 Primary Care Physicians
- 416 eligible
  - 195 responded

Tube feeding prevents/reduces/improves:

- Nutritional status - 93.7%
- Aspiration pneumonia - 76.4%
- Pressure ulcers - 74.6%
- Survival - 61.4%
- Functional status – 27.1%

Underestimate 30 day mortality – 62%

Standard of care
- Is - 51%
- Should be – 26%

SLP recommends – 70%

Request of nursing home staff – 50%

- Human experience
- Religious beliefs
- SNF Regulations
- Financial Incentives
- State laws ACP
Where do we go from here?

- Distinguish advanced v. end-stage/terminal
- Prognostication models
- ACP strategies for specific populations
- Enhanced outcomes studies
- Physician education
  - What is known
  - Ethics
  - Palliative care principles
- Education re: CMS regulations